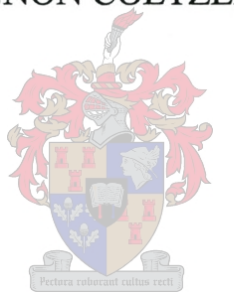
FACTORS AFFECTING QUALITY OF LIFE IN PEOPLE WITH HIV/AIDS: A REVIEW

MIGNON COETZEE



Assignment presented in partial fullfilment of the requirements
for the degree of Master of Arts in Clinical Psychology
at the University of Stellenbosch

Supervisor: Dr Judora Spangenberg
December 2001

DECLARATION OF AUTHENTICITY

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

ABSTRACT

This paper provides an overview and critical evaluation of current (1990-2001) research into Human Immuno-deficiency Virus (HIV) and Acquired Immuno-deficiency Syndrome (AIDS), with particular reference to factors affecting quality of life (QOL) among those living with the disease. A brief look at the importance of optimal QOL when faced with a life crisis such as HIV/AIDS, leads to a discussion of factors influencing QOL in HIV/AIDS. These factors include coping styles, mental adjustment, social support, stigmatization, socio-economic and socio-cultural factors, gender, depression as well as disease progression. The overview is informed by prominent research trends and a critical look at the current understanding of factors impacting on the QOL of people living with HIV/AIDS. Recommendations are made on issues that need further clarification, while future research orientations are also suggested. In the absence of satisfactory treatment strategies or a cure for HIV/AIDS, as well as the evidence of a potential 10 to 12 year life expectancy, there is a pressing need for a better understanding of factors that influence QOL. There is strong support for the notion that QOL directly impacts on disease progression and therefore also on the quality and quantity of survival time. It follows that a better understanding of the nature and determinants of QOL for HIV patients will yield valuable intervention guidelines within a biopsychosocial framework.

OPSOMMING

Hierdie artikel bied 'n oorsig en kritiese evaluering van onlangse (1990-2001) navorsing in die veld van Menslike Immuniteitsgebrek Virus (MIV) en Verworwe Immuniteitsgebrek Sindroom (VIGS), met besondere verwysing na faktore wat bydra tot die lewenskwaliteit van geïnfekteerde indiwidue. Die belangrikheid van optimale lewenskwaliteit teen die agtergrond van 'n lewenskrisis soos 'n MIV-diagnose, word kortliks bepsreek. Daarop volg 'n bespreking van faktore wat 'n invloed het op lewenskwaliteit in HIV/AIDS. Hierdie faktore sluit in hanteringstyl, psigiese aanpasbaarheid, sosiale ondersteuning, stigmatisering, sosio-ekonomies en sosio-kulturele faktore, geslag, depressie asook siekteverloop. Die oorsig word gerugsteun deur prominente navorsingstendense asook 'n kritiese blik op huidige perspektiewe op faktore wat 'n impak het op die lewenskwaliteit van mense wat leef met MIV/VIGS. Aanbevelings word gemaak aangaande aspekte waaroor verdere helderheid verkry moet word, asook oor toekomstige navorsingsvraagstukke. Gegewe die afwesigheid van voldoende behandelingstrategieë of selfs 'n geneesmiddel vir MIV, tesame met die bewys van 'n 10 tot 12 jaar potensiële lewensverwagting, bestaan daar 'n dringende noodsaaklikheid vir grondiger insig in faktore wat lewenskwaliteit beïnvloed. Daar is sterk steun vir die uitgangspunt dat lewenskwaliteit 'n direkte impak het op siekteverloop en derhalwe ook op die duur en kwaliteit van oorlewingstyd. Verbeterde kennis oor die aard en determinante van lewenskwaliteit in MIV-pasiënte sal dus waardevolle inligting kan verskaf in terme van toepaslike riglyne vir intervensies binne 'n biopsigososiale raamwerk.

TABLE OF CONTENTS

FACTORS AFFECTING QUALITY OF LIFE IN PEOPLE WITH HIV/AIDS: A REVIEW

1. INTRODUCTION

This paper provides an overview and critical evaluation of current (1990-2001) research into Human Immuno-deficiency Virus (HIV) and Acquired Immuno-deficiency Syndrome (AIDS), with particular reference to factors affecting quality of life (QOL) among those living with the disease. A brief look at the importance of optimal QOL when faced with a life crisis such as HIV/AIDS, leads to a discussion of variables impacting on QOL in HIV/AIDS. These variables include coping styles, mental adjustment, social support, stigmatization, socio-economic and socio-cultural factors, gender, depression as well as disease progression. The overview is informed by prominent research trends and a critical look at the current understanding of factors impacting on the QOL of people living with HIV/AIDS. Recommendations are made on issues that need further clarification, while future research orientations are also suggested.

In order to contextualize the challenges of living with HIV/AIDS — both internationally and locally — the range and spread of the disease requires some preliminary mention. The dramatic global escalation of the HIV/AIDS pandemic has been termed a slow-wave disaster, leaving in its wake the devastation of individuals, families, communities and economies (Jackson & Kerkhoven, 1995). According to recent global figures released by the World Health Organisation, 70% of the 33.4 million people living with HIV/AIDS are in sub-Saharan Africa (Allen, Simelela & Makubalo, 2000). Despite the relatively late introduction of the pandemic into South Africa, there has been an alarming spread, particularly amongst heterosexual individuals. According to official projections commissioned by the United Nations Development Programme, South Africa's latest HIV seropositivity figures for the year 2002 is in the region of 4.2 million adults and children. It is disturbing to note that this figure was already exceeded during the year 2000 (Whiteside & Sunter, 2000).

The most recent figures released by the government suggest that 4.7 million, or one in nine South Africans ("Een uit 9", 2001), are currently infected with the virus. It is estimated that by the year 2006 no less than 17% of the population will be infected (Swanepoel, 2001). Shocking as these figures might be, they are considered conservative by independent statisticians. A figure in the region of 5.3 to 5.4 million is regarded as more realistic for current infection (Beresford, 2001).

In the light of these statistics it is vital to have a clear grasp of the factors influencing the duration and nature of the viral incubation period, as well as of the factors influencing those suffering from this challenging illness. Both the objective and subjective insights play a significant part in our understanding of the QOL of the continually growing HIV/AIDS population.

While research findings regarding prevention and cure for HIV/AIDS remain inconclusive, survival time for individuals with an HIV diagnosis continues to increase (Catalan, Meadows & Douzenis, 2000). The rapid advance of the disease is characterized by a fluctuating course involving periods of good health followed by periods of ill-health. HIV-positive individuals face an uncertain future, not only with regard to their physical well-being, but because of the constant ebb and flow of new discoveries, new therapies and complex arguments about the aetiology, progression and management of the disease (Chidwick & Borrill, 1996). The media, as well as health care services, have also made a conscious shift away from issues of death and dying. For instance, the expression 'living with HIV/AIDS' has become the public slogan of choice. What remained unaltered, however, is the personal struggle and severe stress linked to an HIV diagnosis. The stress lies not only in the development of the disease but also in the socio-economic and interpersonal consequences associated with a stigmatized, progressive and chronic illness.

2. HIV/AIDS AS A LIFE CRISIS

HIV/AIDS represents a major life crisis with a unique set of stressors that impact on both the individual and the community. Caplan's Crisis Theory (cited in Moos & Tsu, 1977) offers a useful conceptual framework in this regard as it states that a crisis occurs when the situation encountered is so novel and so profoundly challenging that the individual's or society's habitual

responses are considered to be inadequate. Stress results from the imbalance or unstable relationship between the perceived demand and the sense of not being able to meet that demand. Due to its chronic nature the course of the HIV/AIDS disease is characterized by a series of health related and other stress peaks, thus making any equilibrium achieved at best tentative and fragile (Moos & Tsu, 1977).

It follows that in coping with the stress of an HIV diagnosis the individual's perception of the stressor in relation to resources available will directly impact on subjective QOL. Moos and Tsu (1977) provided a useful framework in which physical illness, described as a life crisis, is cognitively appraised by the individual who mobilizes adaptive tasks to which certain coping skills can be applied. The authors further identified three factors influencing the cognitive appraisal, perception of the tasks involved, and selection of relevant coping skills, namely the background and personal characteristics, illness-related factors, and features of the physical and sociocultural environment. This model provides a useful structure within which to explore the complex interplay between and among factors such as social support, coping skills, mental adaptation, disease progression and social environment.

3. THE IMPORTANCE OF QUALITY OF LIFE IN HIV/AIDS

The success with which an individual manages to live with this ongoing stressor impacts directly on their QOL. QOL is a relatively new concept in health care research and has its origin in the field of oncology. In 1988 Frank-Stromborg succinctly pointed out that 'the value of cancer treatment is judged not only by survival but on the quality of that survival' (Grimes & Cole, 1996, p. 691; Griffiths & Wilkens, 1993). It was soon realized that this concept had a broad application in the field of other chronic illnesses such as HIV/AIDS. With the growing understanding of HIV/AIDS, researchers and health care professionals recognized that survival time is not only a question of quantity but also of QOL (Catalan et al., 2000).

Although initial HIV research focused primarily on measuring the effectiveness of medical and pharmacological interventions (Hays & Shapiro, 1992; Lubeck & Fries, 1993; Wu & Rubin, 1992), there is a growing recognition that QOL is an important outcome in and of itself (O'Keefe & Wood,

1996). Facing years of health decline and the escalating onset of debilitating opportunistic infections, the importance of maintaining optimal QOL for persons with HIV is self-evident.

Grimes and Cole (1996) accurately point out how QOL has generally been conceptualized as a functional state rather than as a subjective construct that reflects attitudes and perceptions. Functional status refers to a person's ability to function effectively within a given role or life activity. Within the context of illness it broadly refers to what has been termed 'self-help', in order to describe the ability to manage adversity during illness. Such self-help functionality includes physical mobility, physical ability and social activity (Grimes & Cole, 1996). Although functional status is logically related to the pathology, progression and symptomatology of the disease, there is sufficient evidence to argue that perceived QOL differs conceptually from a functional state. Even though daily functioning may be impaired, an individual can still find pleasure and satisfaction in life. QOL therefore refers less to functional status and more to the subjective appraisal of well-being and level of satisfaction (Grimes & Cole, 1996). Thus a subjective 'sense of meaning and purpose in life' (Hedge, 1991) is dependent on the individual's appraisal of his or her overall physical, psychological and social functioning and directly impacts on the morale, happiness and satisfaction with life (Friedland, Renwick & McColl, 1996; Zarazaga Monzon, Culebras, Gomez Candela & Cos, 1998).

Retaining a sense of personal well-being and purpose in life whilst living with HIV/AIDS is enormously challenging, but crucial in ensuring optimal QOL during a limited quantity of life. Appropriate intervention strategies aimed at enhancing HIV/AIDS-related QOL need to be supported by a clear understanding of the subjective experience of sufferers and require a closer look at the factors that impact on their QOL.

4. FACTORS AFFECTING QOL IN HIV/AIDS

There are numerous variables that have to a greater or lesser extent been shown to correlate with QOL. The following is a brief overview of research studies exploring some key variables in this regard.

4.1 Coping styles

Lazarus and Folkman (1984) defined coping as 'constantly changing cognitive and behavioural efforts to manage the specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (p. 114). Following the initial appraisal of a stressful situation — in this case an HIV diagnosis — and the subsequent appraisal of one's resources to cope with it, a specific coping strategy is utilized (Schreurs & de Ridder, 1997).

Coping styles associated with improved QOL have been prominent in HIV/AIDS research over the last ten years. Due to the limited range of this article a brief overview of the most prominent coping styles will be given, namely active versus passive coping, problem-focused versus emotion-focused coping, and escape or avoidance coping (including denial). As is reflected in the following discussion, these different coping styles represent clusters of behaviour that strongly correlate with QOL.

Within the clusters of problem-focused and emotion-focused coping, certain patterns of QOL outcomes have emerged. The use of problem-focused coping strategies — such as effective stress management and perceived control — seem to have a significantly positive influence and show a positive correlation with improved QOL in HIV/AIDS patients. Conversely, an absence of these attributes have been found to have a significantly negative effect (Chidwick & Borrill, 1996).

A recent longitudinal study of 138 HIV-infected patients in Nebraska confirmed the findings by Friedland et al. (1996), namely that improved QOL was associated with problem-focused coping, while emotion-focused coping, avoidant coping, hopelessness, loss of motivation and negative feelings about the future were predictors of poorer QOL (Swindells et al., 1998; Swindells et al., 1999). In accordance with these findings, De Genova, Patton, Jurich and MacDermid (1994) found a positive correlation between emotion-focused coping and depression.

As is the case with problem-focused coping, an active coping style indicates a pro-active cognitive and behavioural engagement with the realities of being HIV-positive, and strongly correlates with improved QOL (Abetz, McGrath, Grant & Anderson, 1998; Blaney et al., 1992; Friedland et al., 1996; Goodkin et al., 1992a; Heckman, Somlai, Sikkema, Kelly & Franzoi, 1997; Pepler et al., 1998; Stowe, Ross, Wodak, Thomas & Larson, 1993)

Passive coping, on the other hand, has not only been linked to poorer QOL but also to the clinical progression of HIV to AIDS (Byrnes et al., 1997; Goodkin, Fuchs, Fester, Leeka & Rishel, 1992b; Goodkin et al., 1992a). Moneyham et al. (1998) investigated the effectiveness of active and passive coping strategies in a sample of 264 women. Active coping, which included activities such as seeking social support, managing the illness and engaging in spiritual activities, appeared to serve a protective function in that emotional distress decreased with greater use of active coping, even as physical symptoms increased. Passive coping, as indicated by avoidance behaviour, had no such protective effect against emotional distress. Interestingly, the use of avoidance coping decreased and active coping increased as physical symptoms increased, suggesting that active coping is more likely to be used as levels of physical symptoms rise.

In a study of 167 men Pepler et al. (1998) found that active coping and a sense of control were associated with health in HIV-positive individuals. They also concluded that when passive and avoidant coping strategies were employed, respondents often recognized the ineffectiveness and undesirability of these patterns — this potentially added to their frustration with the illness and exacerbated their emotional distress. This study not only emphasized the importance of active coping, but also the perceived effectiveness of such coping strategies.

Despite the presupposition that the stresses and demands encountered by women are unique and that their life coping strategies differ from men, supporting gender based research is scarce. Rose and Clark-Alexander (1996) explored the QOL and coping style of women with children and identified three styles of coping: confrontative coping (used most frequently), and passive and emotive coping (used less often). Contrary to expectation, Siegel, Gluhoski and Karus (1997a) found the coping style and mood of HIV-positive women to be similar to that of men, with escape-avoidance coping being closely associated with negative emotions.

In a study of the 'fighting spirit' coping style among 58 HIV-positive women, it was found that low scores on loneliness, anger and depressive symptoms significantly predicted high scores on fighting spirit (Nannis, Semple & Patterson, 1995; Nannis, Patterson & Semple, 1997). A recent study by Grassi, Righi, Sighinolfi, Makoui and Ghinelli (1998) confirmed that patients who were

adjusting well to their HIV-positive status tended to have a higher level of fighting spirit and lower degrees of hopelessness.

Fighting spirit as a form of active coping, has been found to correlate positively with improved QOL in HIV/AIDS (Grassi et al., 1998; Zander et al., 1993). Leserman et al. (1992) reported that adopting a fighting spirit, reframing stress to maximize personal growth, planning a course of action, and seeking social support were associated with a better prognosis.

In a four-year longitudinal German study 43 subjects reported on their QOL, depressive reactions and coping styles. A decrease in evasive-regressive coping in favour of enhancement of emotional palliative and goal-oriented coping strongly predicted improved QOL (Brieger, Leiberich, Schumacher & Low, 1996). Similar findings were obtained in another longitudinal German study of 61 HIV-positive persons. Evasive-regressive coping was found to be positively correlated with reduced QOL and was most commonly used by intravenous drug users (Leiberich et al., 1993).

Likewise, escape-avoidance coping has been associated with symptoms of psychological distress (such as depression and self-blame), an external locus of control and overall reduced QOL (Chidwick & Borrill, 1996; Crystal, Bilder, Merzel & Sambamoorthi, 1993; Grassi et al., 1998; Kalichman, Sikkema & Somlai, 1996; Singh et al., 1998; Swindells et al., 1998). In a study of subjective attribution theories on coping and psychological functioning among homosexual men with HIV, self-blame was associated with an avoidant coping style while both of these were in turn associated with depressive mood and life dissatisfaction (Clement & Schonneson, 1998). A Japanese study of 50 HIV-positive patients confirmed that depressive symptoms and somatic complaints, signalling poor QOL, were significantly positively correlated with avoidance coping responses (Fukunishi, Hayashi, Matsumoto, Negishi & Moriya, 1997).

Denial, as a form of escape-avoidance coping, has been the subject of much research and deserves a more in-depth exploration. Denial falls within the emotion-focused ambit of coping skills, but does not summarily rule out simultaneous problem-focused coping strategies. The theoretical framework pertaining to the concept of denial had its origin in Lindemann's grief work, where it was argued that the presence of avoidance and denial prevented the individual from fully

negotiating the bereavement crisis. Lipowski further described instances of partial, tentative or minimal denial as minimization (Lazarus, 1981).

It has further been suggested that denial/avoidance is the opposite of vigilance. Janis and Mann (Horowitz, 1978) point out that vigilance is desirable as it mobilises a search for information and the consequent weighing-up of alternative coping strategies. Horowitz (1978) supported this notion by referring to the process of worrying (preoccupation with unwanted intrusion of thoughts and images related to a threat) as the opposite of denial. Denial and avoidance obstruct successful mastery of a threat by preventing successful cognitive coping prior to a stressful confrontation. Research studies in the fields of oncology and cardiology confirmed these findings as avoidance of initial signs of illness resulted in delayed medical intervention and poorer prognoses (Lazarus, 1981).

Accordingly a seven-year prospective study conducted in America, confirmed that a more rapid progression of AIDS was associated with the use of denial as a coping mechanism (Gale, 2000). In addition, a study conducted in a homosexual symptomatic seropositive male community revealed that denial coping was closely associated with impulsive and self-destructive behaviour such as drug/alcohol abuse or high-risk sexual behaviour (Pivar & Temoshok, 1990) which in turn lead to a reduction in QOL.

Denial can, however, be viewed as an adaptational response that allows the individual to cope with an initial shock while buying time to make the necessary cognitive adjustment. Lazarus (1981) distinguishes between denial with a negative outcome and denial with a positive outcome. He suggests that denial might be helpful within a limited time frame, but that it might become dysfunctional as time passes. Kubler-Ross refers to the temporary disavowal of reality as a means of getting through the initial devastating early period of loss and threat, before reaching the later stage of acknowledgement and adjustment (Lazarus, 1981).

Active coping and emotional palliative coping on the other hand has been associated with an internal locus of control and improved QOL (Abetz et al., 1998; Brieger et al., 1996; Heckman et al., 1997; Hedge, Slaughter, Flynn & Green, 1993; Pepler et al., 1998; Singh et al., 1998; Wolf et al., 1991; Zander et al., 1993). Locus of control refers to the beliefs or cognitions that

individuals hold with regard to the ways in which a given outcome occurs. Internal locus of control therefore suggests that the outcomes occur due to something inside the person and under his or her control, while external locus of control implies that the outcome is dependent on people or factors outside the person.

Research findings confirm the positive correlation between external locus of control and increased levels of distress in the face of negative life events. A sense of powerlessness or helplessness is likely to develop should a person not have a sense of mastery, or belief in the ability to control the world and affect outcomes (Lefcourt, 1981). Hopelessness, loss of motivation and negative feelings about the future were predictors of poorer QOL (Grassi et al., 1998; Osowiecki et al., 2000; Singh et al., 1998;)

Previous research strongly suggests that existential well-being or spiritual activities positively correlate with improved QOL (Bloom, 1996; Cohen, Hassan, Lapointe & Mount, 1996; Green, Henderson, Tyrer & Hedge, 1992; Griffiths & Wilkens, 1993; Mellors, Riley & Erlen, 1997; Sowell et al., 2000; Stevens & Tighe Doerr, 1996). One could hypothesize that spiritual activities are an important psychological resource accounting for individual variability in adjustment to the stressors associated with HIV/AIDS disease, or that it gives people access to social support structures. Further research is however required to facilitate a better understanding of the interplay between these factors.

Pivar and Temoshok (1990) stress the need for an in-depth understanding of how individuals cope with HIV/AIDS-related stressors in order to develop appropriate psychosocial interventions. This could also serve as a means of identifying and supporting individuals whose coping strategies lead to increased psychological, social and physical vulnerability.

Coping is not a static or inflexible phenomenon, but a continuous and constantly changing process whereby the individual takes the necessary steps to deal with stress. HIV/AIDS thus represents a complex host of ever fluctuating stresses. Investigations into coping styles and their relationship to QOL need to take cognisance of the subjective appraisal of these cumulative stresses as well as of the contextual, rather than the inherent functionality, of a particular coping style. This opens up a rich and as yet under-explored field of research which could lead to a better understanding of

the challenges associated with different stages of the disease, while directly informing appropriate intervention strategies.

4.2 Mental adjustment

As mentioned, coping and mental adjustment show significant conceptual overlap and are often used interchangeably. However, research has not yet explicated the difference between these two constructs. Greer and Watson (1987) attempted to distinguish between them by defining mental adjustment as comprising two aspects: cognitive appraisal and ensuing reaction (such as coping strategies). Likewise, it could be argued that coping style consists of an appraisal element followed by a behavioural, reactive component and that these two concepts essentially refer to the same thing. As can be gleaned from the discussion above, the HIV/AIDS literature has mostly referred to coping style as opposed to mental adjustment (Ross, Hunter, Condon, Collins & Begley, 1994). The notion of mental adjustment — like QOL — also had its origin in cancer research where the correlation between appraisal, coping and psychological adjustment and QOL have been investigated (Grassi, Rosti, Lasalvia & Marangolo, 1993; Greer, Morris & Pettingale, 1979; Pinder, Ramirez, Richards & Gregory, 1994). In line with the research on coping style and QOL, these studies also identified disease outcome and psychological adjustment as critical factors in the QOL experienced by individuals suffering from a chronic and potentially terminal illness such as HIV/AIDS.

The Mental Adjustment to Cancer Scale (Watson, Greer & Bliss, 1989) offered a basis for further exploration of adjustment to life for people suffering from chronic illness. Ross et al. (1994) modified this well established scale for HIV/AIDS (the Mental Adjustment to HIV Scale or MAHIVS) and administered it to 107 Australian men with HIV infection. This and subsequent studies, utilizing the MAHIVS, highlighted a number of subscales or domains confirming the close link between coping style and mental adjustment. These include hopelessness/helplessness, a belief in ability to influence the course of the illness, a fighting spirit, denial/avoidance and a fatalism subscale.

In similar fashion to the coping style research, poor QOL showed a strong correlation with certain mental adjustment subscales. Grassi et al. (1993) found an association between lower fighting

spirit scores, greater hopelessness and elevated psychological morbidity. Fighting spirit was found to be the most adaptive end of the continuum with helplessness/hopelessness the least adaptive. As can be gleaned from the above studies, the parallels with coping style research is apparent, suggesting the need for these concepts to be integrated into one measuring instrument, and for consensus to be reached regarding the domains measured.

Kelly et al. (2000) conducted an Australian study of 164 HIV-positive men, measuring their psychological adjustment to HIV. The four factors identified were hopelessness, fighting spirit/self-efficacy, personal control, and minimization. Predictably, fighting spirit emerged as a potential indicator of psychological resilience, whereas hopelessness was significantly associated with psychological symptoms and concurrent major depression.

The literature on mental adjustment to HIV/AIDS includes two further noteworthy studies. Spalding (1995) conducted a study of racial minorities and other high-risk groups with HIV/AIDS, examining levels of perceived locus of control over health status and whether different health locus of control orientations determined psychological adjustment as measured by intrusive thoughts, depression and avoidant thoughts. External locus of control and a belief that health status was in the hands of powerful 'others', or was even a matter of chance, were more common amongst minorities, and correlated with poorer psychological adjustment. In addition, women of lower socio-economic status were found to be psychologically more vulnerable.

Siegel, Karus and Raveis (1997b) explored whether reported levels of psychological and/or psychosocial adjustment for HIV-positive women varied with regard to race and ethnicity. The sample consisted of 146 HIV-infected African American, Puerto Rican or White non-Hispanic women in New York City. The results confirm the elevated vulnerability of all groupings, but also revealed interesting between-group differences with Puerto Rican women being most vulnerable. Siegel et al. (1997b) stress the need for further research into specific factors that impact on the psychological and psychosocial adjustment of these women, so as to be able to streamline interventions accordingly.

It has been hypothesized that the improvement in QOL results from better adaptation to the disease (Friedland et al., 1996). As the individual makes the necessary adjustments to personal

health expectations, the appraisal of disruptions no longer exceed the appraisal of coping skills and inner resources (Fell, Newman & Herns, 1993). In a study of 669 patients over a 12 month period, Lubeck and Fries (1992) found that symptomatic or AIDS patients had significant declines in all aspects of role functioning and disease symptoms, but no significant declines in cognition or mental health.

It has also been reported that receiving an HIV diagnosis can have an enhancing effect on QOL. The major factor correlating with this is being at peace with God and the universe. In a phenomenological study conducted by Coward (1994) women described their HIV diagnosis as being an 'opportunity' to make a difference and have a purpose in life. Future research could further explore these and other underlying cognitions that lead to improved adaptation.

The above research findings highlight cognitive appraisal, mental adjustment and consequent style of coping as crucial determinants of QOL. As can be gleaned from the brevity of the literature overview, mental adjustment is not a widely used term and as such lacks sufficient theoretical and research back-up in the field of HIV/AIDS. Future research orientations need to include clarification about the terminology and domains measured. This is an issue that requires both theoretical and investigative attention and could serve to enhance the focus of HIV/AIDS-related QOL research. Even more challenging would be an investigation into the nature and direction of the relationship between mental adjustment to HIV/AIDS and factors such as stigmatization or social support, and how these serve to alleviate or aggravate the stress of living with the illness.

4.3 Social support

Social support has been a strong focus of the stress-outcome paradigm within the subjective conceptualization of QOL for HIV-positive patients. Broadly speaking it has been viewed as a generic construct that includes structural characteristics of social networks as well as functional aspects of social interactions. There is a wide range of psychometrically sound measuring instruments with some variation in terms of their primary focus.

Vaux (1990) refers to the term 'social support' as a meta-construct relating to different aspects of social relationships, including the existence, quantity and type of interpersonal relationships

(network structure or social interaction); the functional content of these relationships (emotional, psychological, tangible or informational support); and the perceived quality or adequacy of this support (subjective appraisal).

Following a comprehensive social support review compiled by Cohen and Willis (cited in Stowe et al., 1993), three hypotheses with regard to the impact of social support on QOL have been suggested. The main effects theory posits that social support directly contributes to health outcomes. The perception that one is supported by others impacts positively on people's psychological states, which in turn has a positive influence on both the immune system and daily functioning.

The second is known as the buffering hypothesis, stating that the support and resources provided by others protect people from the pathogenic effects of stress. When considering the persistent levels of heightened stress associated with an HIV diagnosis, social support as a buffer against stress, is of particular interest. The third hypothesis is an extension of the second in that it sees social support as buffering the negative health outcomes that result from stressors, including the stress of serious illness (Friedland et al., 1996).

It has been suggested that the absence of a clear and satisfactory theoretical framework has resulted in research that is primarily data-driven (Sarason, Sarason & Pierce, 1997). Numerous studies have, however, confirmed the positive correlation between the availability of social support or supportive relationships and improved QOL (Di Franceisco, Heckman & Somlai, 1997; Donini, Mirandola, Galvan, Serpelloni & Kozina, 1992; Heckman et al., 1997; Nunes, Raymond, Nicholas, Leuner & Webster, 1995; Singh et al., 1998; Swindells et al., 1998; Stowe et al., 1993; Mello, 1996; Schreurs & De Ridder, 1997).

Friedland et al. (1996) differentiates between informational, instrumental and emotional support and its relative or perceived value at different stages in the process of disease progression. Research has indicated that the availability of instrumental and informational support directly impact on QOL (Mello, 1996; Singh et al., 1998; Zander et al., 1993). In a study of 455 gay and bisexual men, Hays, Turner, Catania, Mandell and Coates (1998) found all types of social support

to be associated with reduced depression, but also found informational support to be especially beneficial for those in early stages of the disease.

In general, social support is more readily shown to be associated with psychological well-being (Green, 1993; Kennedy et al., 1998; Lamping et al., 1992). Zich and Temoshok (1987) confirmed that emotionally-sustaining support was viewed as more desirable, used more often and more useful when used. In a comparative longitudinal study of 165 HIV-positive and 179 HIV-negative intravenous female drug users, Brook et al. (1999) indicated that initial high scores on psychosocial domains significantly predicted adaptive coping strategies such as problem solving and seeking social support while poor psychosocial functioning predicted maladaptive coping.

Likewise, conflictual relationships, reflecting poorer social support, have also been related to reduced QOL. In a study of 510 urban based HIV-positive women, McDonnell, Gielen, O'Campo and Burke (1999) discovered significantly lower QOL among women involved in abusive relationships. Fleischman et al. (2000) investigated the interrelationships among coping, conflictual social interactions and social support, as well as their combined associations with positive and negative mood. They found that conflictual social interactions positively correlated with social isolation, anger and wishful thinking as well as negative mood. In comparison with social support, conflict in social interactions was a stronger determinant of negative mood. Their findings point to the importance of simultaneously considering coping, supportive relationships and social conflict.

The availability and nature of social support reflect prevalent societal attitudes and perceptions to HIV/AIDS. It is the realm where HIV-related social prejudice and stigmatization manifest most clearly and impact most strongly on QOL (Alonzo & Reynolds, 1995; Gillman & Newman, 1996; Reid, 1994; Van Zyl, 1999).

Secondary to the emotional distress caused by social prejudice is the stigma attached to the illness. This often makes it difficult for individuals to obtain and secure certain forms of support. Other difficulties related to the availability and adequacy of social support include the lack of resources, the high incidence of the disease within the social network which depletes potential sources of support, and the erratic progression of the disease which makes it difficult for

caregivers to sustain the high levels of support needed (Folkman, Chesney & Christopher-Richards, 1994). It has also been well documented that people with AIDS are often alienated, both emotionally and geographically, from the natural support group of their own families (Green, 1993; Turner et al., cited in Friedland et al., 1996).

Interestingly, an American study found that seropositive women had greater avenues of social support and more socially based coping strategies than seronegative women. The same tendency was not found in men (Solomon, Cleghorn, Astemborski & Vlahov, 1993).

There is still much to be written about the complexity of social support, its applicability, and the causal process through which this influences perceived QOL. In general, the literature implicitly refers to social support as positively impacting on QOL. However, Sheurs and De Ridder (1997) challenge the notion that social support is by definition supportive, and correctly point out the need for a social-support concept that will envelop both its positive and negative effects. Their suggestion opens a new dimension in the area of social support research.

Future developments need to be directed at establishing a sound theoretical basis for research on social support as a key determinant of QOL in HIV. Thus far the literature has made certain useful suggestions, none of which has been adequately supported by empirical studies. Lazarus and Folkman (1984) referred to social support as a coping strategy, whereas Thoits (1986) saw social support as a coping resource (coping assistance) which precedes the coping process. He described it as 'the active participation of significant others in an individual's stress-management efforts' (p. 417). It has also been suggested that social support is dependent on coping, implying that social support follows as a result of an individual's way of coping (Vaux, 1990). Within this context, it might be possible to integrate models of coping and support (e.g. problem-focused coping and instrumental support; emotion-focused coping and emotional support; perception-focused coping and informational support) (Friedland et al., 1996).

In an attempt to find a theoretical framework for understanding the role of coping and social support in chronic illness, authors have referred to the transactional stress-coping model proposed by Lazarus and Folkman (1984). However, Schreurs and De Ridder (1997) point out that the assessment tools based on this theory fail to reflect the needs specific to individuals suffering from

chronic illness and therefore provide little insight into their unique and varied adaptation strategies.

4.4 Stigmatization

Social prejudice and stigmatization are commonly regarded as the root causes of social isolation experienced by those suffering from HIV/AIDS. Already in 1992 the United Nations World Health Organisation (UNIADS WHO) declared discrimination one of the pivotal concerns in developing a social policy for HIV/AIDS. This was supported locally by Lindegger and Crewe (1997) who anticipated the need for a comprehensive mental health policy around HIV/AIDS — a policy that nurtures non-discrimination, fosters respectful and empathic environments and enhances QOL (Strebel & Lindegger, 1998).

Despite numerous efforts to change public attitudes, the reality reflected in the literature is characterized by deeply ingrained social prejudice, stereotyping and stigmatization. Lutgendorf et al. (1994) discuss how the resurgence of stigmatization and self-doubt affect the individual's sense of identity and well-being while negatively impacting on QOL. It is not surprising then that stigmatization has been identified as one of the major stressors and obstacles in the lives of HIV-positive individuals and those close to them (Du Plessis, Meyer-Weitz & Steyn, cited in Lindegger & Wood, 1994).

Wide-ranging studies indicate that social prejudice and stigmatization lead to fear of rejection, guilt and shame while increasing the prevalence of anxiety, depression and withdrawal (Green, 1993; Lie & Biswalo, 1996; Lippmann, James & Frierson, 1993; McGrath, Ankrah, Schumann, Nkumbi & Lubega, 1993; Meredith, Delaney, Horgan, Fisher Jr & Fraser, 1997). To this end, having transmitted the virus to a partner or infant further complicates the psychological adjustment and exacerbates feelings of guilt, self-blame and negative self-rating (Crandles, Sussman, Berthaud & Sunderland, 1992; Lippmann et al., 1993; Stevens & Tighe Doerr, 1997; Taylor-Brown, 1993;)

Apart from the apparent detrimental effect on psychological QOL, stigmatization has also been found to positively correlate with limited daily functioning (Sowell et al., 1997). Similarly, fewer

incidents of AIDS-related discrimination and stigma predicted higher levels of general life satisfaction (Heckman et al., 1997).

However, to fully understand the impact of stigmatization an in-depth exploration of the discourses supporting HIV/AIDS-related social prejudice is required.

There is a deluge of research about general attitudes towards HIV/AIDS, indicating that for many it remains a disease of the 'other' coupled with an active aversion to the disease and of those involved with it (Grundlingh, 1997; Van Zyl, 1999). There are a number of factors contributing to the prejudice and discrimination underpinning dominant discourses around HIV/AIDS in South Africa, most of which propagate popular beliefs that HIV/AIDS is the 'just desert' of those labelled as immoral and deviant, and the notion that only certain sub-groups — such as gay men, intravenous drug users, prostitutes and the promiscuous — are at risk (Alonzo & Reynolds, 1995; Gillman & Newman, 1996; Reid, 1994). Infection of heterosexual individuals has been popularly ascribed to sexual deviance, promiscuity and sexual risk taking, thus reinforcing a long history of 'victim blaming' and 'scapegoating' (Aggleton & Homans, cited in Grundlingh, 1997; Green & Rademan, 1997; Van Zyl, 1999).

Furthermore, Grundligh (1997) refers to the triple stigma of HIV/AIDS as society views sufferers as members of a stigmatized group, infected with a sexually transmitted disease and suffering from a terminal illness characterized by an unaesthetic death (Green & Rademan, 1997; Grundlingh, 1997; Lie & Biswalo, 1996). The result has been a shocking situation where the terminally ill are often seen as unworthy of, or not qualifying for, sympathy (Weeks, cited in Grundligh, 1997).

Against this background, the infected subjects carry the burden of stigmatization and suffer from isolation, abandonment, loss of social support as well as unemployment (Lippmann et al., 1993). The socio-economic consequences of the illness lead to further marginalization with devastating social and political consequences (Lindegger & Wood, 1994). The impact of stigmatization within the gay community has received most attention with studies confirming the isolation that results from a fear of disclosure (Britton, Zarski & Hobfoll, 1993) and potential social ostracism (Rosengard & Folkman, 1997).

Apart from the alienation and isolation caused by social prejudice, there is the further complication of the individual internalising society's prejudicial attitude which in turn leads to negative self-rating, depression and even suicidality (Lippmann et al., 1993). The fear of being stigmatized has been found to increase the individual's sense of isolation and lack of control (Pizzi, cited in Meredith et al., 1997).

Goffman (cited in Green & Rademan, 1997) described how stigmatized individuals incorporate and internalize standards from their wider community and consequently discredit and even despise themselves. Thus negative attitudes from others serve to pattern the individual's self-concept in a self-fulfilling manner, resulting in isolation from self and others (Alonzo & Reynolds, 1995; Williams, cited in Green & Rademan, 1997). In a comparative study, for instance, rural HIV-positve individuals experienced more community stigma, a heightened personal fear of public exposure and significantly lower satisfaction with social support and life in general, than their urban counterparts (Heckman, Somlai, Kalichman, Franzoi & Kelly, 1998).

What complicates matters is the fact that the withdrawal, silence and isolation caused by stigmatization, deprive the individual of opportunities for much needed support from families, friends and health care staff (Friendland et al., 1996; Sowell et al., 1997). Lie and Biswalo (1996) point out that the stigma associated with HIV, as well as the link between sexuality and a lethal disease, will have an effect on persons' choice of whom they will turn to for support. In Lie and Biswalo's (1996) Tanzanian study of 611 HIV-positive individuals they found that fear of rejection, shame and guilt prevented individuals from informing significant others of their status. Living with the fear of rejection is an ongoing psychological stressor and often lead to the adoption of avoidant coping strategies such as denial. The secrecy surrounding an HIV diagnosis reinforces the discourse of silence. Fear of discrimination not only prevents individuals from accessing potential support structures, but also from seeking timeous help from health care systems (Karim, 1998).

Stigmatization is regarded as one of the major sources of preventable suffering for persons living with HIV/AIDS and should therefore be treated as a research priority. Karim (1998) argues for strategies that will encourage disclosure and thereby overtake the silence induced by

stigmatization and discrimination. The first step towards such strategies involves focused research that will establish the nature, extent and impact of stigmatization.

4.5 Depression

Depression is not only related to current life crises, but is also a reflection of an individual's premorbid personality and innate ability to mobilize inner and outer resources alike.

Receiving an HIV diagnosis is a traumatic event characterized by reactions of shock, anguish, disbelief and often suicidality (Platt, cited in Green, 1993; Sewpal & Mahlalela, 1998; Stevens & Tighe Doerr, 1997). Typical also is a consequent loss of self-esteem, increased levels of anxiety, feelings of isolation and symptoms of depression (Berer & Ray, 1993).

There is general agreement about the strong positive correlation between depressive symptoms and a decrease in QOL (Fukuda, 1994; Grassi & Sighinolfi, 1996; Ling et al., 1998; Maldonado et al., 1998; Moneyham, Sowell, Seals & Demi, 2000; Rubin et al., 1994), particularly in early asymptomatic HIV disease (Catalan, 1990). This was confirmed in an extensive study of comorbid psychiatric conditions of 2864 HIV-positive subjects. Individuals with a probable mood disorder diagnosis had significantly lower scores on health-related QOL measures than those without depressive symptoms (Sherbourne et al., 2000).

All of these responses have a negative effect on a person's subjective perception of QOL. Sherbourne et al. (2000) confirmed that HIV-positive subjects with a probable mood disorder diagnosis had significantly lower scores on health-related QOL measures than did those without symptoms.

Living with an HIV diagnosis constitutes an ongoing strain which predisposes the individual to depression. Periods of increased vulnerability have been identified as occurring shortly after diagnosis as well as during periods of increased physical symptoms (Thompson, Nanni & Levine, 1996). Most research shows that a decline in health often signals the onset of a myriad of psychosocial stressors, such as loss of employment. These stressors also have an adverse effect on the individual's psychological well-being and mood. It is not surprising that Thompson et al.

(1996) found a positive correlation between the number of strains experienced and the number of depressive symptoms reported by HIV-positive individuals. Three particular factors were identified as most distressing and contributing most to reports of depression and reduced QOL: financial or housing problems, interpersonal relationships and the death or illness of a close other.

Grassi and Sighinolfi (1996) confirmed that depression had a negative effect on some of the dimensions of QOL and singled out the ability to conduct a normal life and to maintain personal care. In addition, pre-existing personality traits such as a fatalistic outlook on life and feeling powerless to change the course of events, positively correlated with HIV-related depression.

In a report on anxiety and depression among HIV-infected heterosexuals in India, Chandra Ravi, Desai and Subbakrishna (1998) found the presence of AIDS in the spouse to be a factor associated with increased emotional distress and furthermore identified pain, poor family relations and concurrent alcohol abuse as of equal significance. They found depression among 40%, anxiety among 36% and suicidal ideation among 14% of individuals within four to six weeks after diagnosis.

Even though the prevalence of suicidal ideation as reported above was relatively low, Lippmann et al. (1993) describes it as an acute and chronic concern, marking the intensity of grief and despondency associated with the disease.

Given the association between depression and suicidality, it logically follows that times of high risk would correspond with periods of increased depression. Thus suicidal ideation has been most prominent within six months of diagnosis (Glass, cited in Rosengard & Folkman, 1997) as well as during times of declining health (Sherr, cited in Rosengard & Folkman, 1997). A three-year longitudinal study by Rabkin (cited in Rosengard & Folkman, 1997) found that the strongest predictors of suicidal ideation were suicide attempts and depression that predated an HIV/AIDS diagnosis. Future research needs to consider not only the correlation between, but also the direction of causality between premorbid personality, psychological mood disturbance and disease progression (Catalan, 1990; Chandra et al., 1998; Murphy & Melby, 1999).

A further factor associated with increased levels of depression and suicidality is previous exposure to others who have died of AIDS (Lippmann et al., 1993). Higher levels of emotional distress have been reported by HIV-positive individuals who have experienced an HIV-related bereavement (Chidwick & Borrill, 1996; Lutgendorf et al., 1994; Manck et al., 1998; Martin & Dean, cited in Sikkema, Kalichman, Kelly & Koob, 1995). The existing body of research conducted within the gay community suggests a gradual shift towards a greater acceptance of death and AIDS-related bereavement. Following a longitudinal study, Neugebauer (cited in Sikkema et al., 1995) observed a decrease in the adverse effects of losses over the second decade of AIDS among gay men. This was confirmed by Martin and Dean (cited in Sikkema et al., 1995) who found that generalized distress weakened over the course of the epidemic and that concern over one's own health and physical functioning, rather than a focus on AIDS-related losses, moved to the foreground.

The literature of the past decade suggests a particular interest in the relationship between depression and coping style, as well as its impact on QOL. Avoidant coping (Fleischman et al., 2000; Krikorian, Kay & Liang, 1995) and evasive regressive coping (Leiberich et al., 1997; Brieger et al., 1996) have been strongly associated with psychological symptoms such as depression and anxiety (Kelly et al., 2000; Crystal et al., 1993) as well as life dissatisfaction (Clement & Schonneson, 1998; Fukunishi et al., 1997; Leiberich et al., 1993; Siegel et al., 1997a; Wolf et al., 1991).

An active coping style on the other hand has been shown to correlate positively with improved mood and a better QOL. Folkman et al. (cited in Kelly et al., 2000) further reported that specific coping response — such as planful problem-solving, seeking advice, gathering information and securing social support at the onset of HIV-related symptoms — have been associated with lower levels of depressive symptoms. Social support has also been identified as a factor impacting on depression among HIV-positive individuals. In this regard Kelly et al. (2000) found that individuals with good social support and an ability to express their emotions, had fewer symptoms of depression.

A correlation has also been found between the perceived availability of social support and depression. An investigation into the association between depression and social support concluded that unsupportive social interactions predicted a significant amount of variance in

depression, beyond the variance accounted for by physical functioning and positive social support (Ingram, Jones, Fass, Neidig & Song, 1999). Individuals perceiving a lack of social support and reporting less satisfaction with this support, displayed increased levels of depression (Green, 1993; Ling et al., 1998; Zich & Temoshok, 1987). Again future research needs to focus on the direction of causality, as it is unclear whether depression is a consequence of poor social support, or whether the presence of depression influences the subjective evaluation of the social support available.

Investigations into the impact of depression on QOL within an HIV/AIDS population need to go beyond the measuring of symptoms. What is required is a comprehensive approach that takes into account the multi-directional interplay of variables and offers more sophisticated insights into the unique character of HIV-related depression. However, first and foremost all future studies need to focus on the development of a measuring instrument capable of distinguishing between symptoms of depression and the physical symptoms of the disease.

As has been pointed out by Thompson et al. (1996), the levels of depression and anxiety among HIV-positive individuals often do not fall within the range of clinical diagnosis. Even though this indicates an ability to cope with the stress of infection, it has a notable impact on the QOL of the individual and should therefore be targeted as a significant point of intervention.

4.6 Socio-economic and socio-cultural factors

Even though epidemiological trends present AIDS as a non-discriminatory disease which threatens every individual, the pandemic has increasingly been presented as reinforcing social inequalities of gender, status, race and sexuality. It is therefore surprising that the potential influence of socio-economic and socio-cultural factors on QOL has received relatively little attention in the research.

Within the multi-cultural South African population where socio-demographic factors are deeply interwoven with a socio-political history characterized by complex and unequal power relations, this is a research priority. The locally emerging pandemic profile not only reflects a strong association with poverty (Karim, 1998; Tallis, 1998), but confirms the notion that those who are

marginalized by social prejudice, discrimination, economic inequalities and political injustices are indeed most vulnerable to the disease (Crewe, 1992; Evian, 1993; Reid, 1994; Gregson, 1994).

It can be hypothesized that these more vulnerable individuals in society start out with a poorer QOL which becomes the baseline subsequent to diagnosis. In addition there is sufficient evidence that, due to their socio-economic and socio-cultural circumstances and vulnerable status, these HIV-positive individuals face greater obstacles which further challenge QOL. For instance, limited access to care, as is often the case in disadvantaged communities, has been found to have a negative impact on QOL with the poor being yet again at greatest risk (Cunningham et al., 1995; Cu-Uvin, Flanigan & Rich, 1996; Heckman, Somlai, Kelly, Stevenson & Galdabini, 1996; Sowell et al., 1997). In their study of health-related QOL Cunningham et al. (1998a) concluded that access to care predicted better physical and mental outcomes. Friedland et al. (1996) found higher income to be positively related to improved QOL in a sample of 120 HIV-positive adults. However, unemployment was high even amongst the healthy and well-educated respondents. The impact of this phenomenon on QOL is profound and requires further attention.

Heckman et al. (1998) investigated the QOL of 276 rural and urban people in large metropolitan areas. Compared with their urban counterparts, rural people with HIV/AIDS reported a significantly poorer QOL, lower perceptions of social support, reduced medical and mental health care and more maladaptive coping strategies.

Given the diversity of cultures, languages, levels of education and socio-economic status within the South African population, there is an urgent need for more in-depth, local studies of the impact of socio-economic and socio-cultural factors on the QOL of those infected with HIV.

4.7 Gender

Gender has featured as a significant and often inter-related socio-demographic factor in QOL research. Referring specifically to sub-Saharan Africa, Karim (1998) highlights the fact that many women, especially those who have only known poverty, have unequal access to resources and have always lived with risk of some kind which seriously impacts on their ability to promote and maintain their own health and well-being. HIV becomes yet another challenge in their quest for

psychological and emotional survival. Gender constitutes a significant field of study warranting a more extensive discussion.

Given the fact that women in general, but particularly those of childbearing age and from disadvantaged communities, are at greatest risk of contracting the virus, they currently constitute the fastest growing segment to be diagnosed HIV-positive. It has often been argued that the relevant research literature reflects a gender neglect with most studies focusing on the gay male population (Di Franceisco et al., 1997; Sarna, Van Servellen, Padilla & Brecht, 1999; McDonnell et al., 1999; Sowell et al., 1997; Lamping, Dooley, Murcott & Renton, 1996). Recent literature favours the position that factors impacting on the QOL for HIV infected women differ from that of men (Cu-Uvin et al., 1996), as well as from that of women suffering from other chronic illnesses (Lamping et al., 1996). In assessing QOL in women with HIV/AIDS Coons, Harwell, Witek, Spence and Striepe (1997) stress the importance of also considering the social and relational context of their lives. Determinants such as socio-economic dependence, level of education, relationship status, role as family caregiver and culturally supported gender roles have been considered as gender specific antecedents to QOL (Campbell & Kelly, 1995; McDonnell et al., 1999; Meredith et al., 1997; Sundby, 1999; Sowell et al., 1997; Shumaker, Ellis & Naughton, 1997).

Comparative studies of QOL in HIV-positive and HIV-negative men and women have confirmed the changes in QOL associated with the disease, while also shedding light on the issue of gender differences. Gender differences have mostly been identified in the domain of symptoms and clinical manifestation of HIV/AIDS (Stevens & Abercrombie, cited in Sarna et al., 1999), with women generally reporting more severe symptoms (Breitbart et al., 1996) and emotional distress than men (Kennedy, Shurnick, Foley & Louria, 1995; Melnick, Sherer & Louis, 1994; Semple, Patterson & Temoshok, 1993). In a recently developed Living with HIV Scale, Holzemer, Gygax, Skodol, Kemppainene and Coleman (1998) found women to score significantly higher on QOL. This finding seems to contradict the previous findings where women tended to score lower on QOL. This discrepancy could, however, be ascribed to the differences in measuring instruments, and therefore requires further investigation.

In a US study of 36 female and 85 male HIV-positive respondents, Avis, Smith, Mayer and Swislow (1997) found few gender differences in terms of QOL. The only significant difference was in the

domain of physical functioning with female respondents reporting lower scores, even after controlling for symptoms and CD4 counts. These findings raise the question as to whether HIV/AIDS may have a differential effect on women in terms of physical functioning.

Two pertinent studies conducted outside the ambit of first world socio-economic and medical conditions presented contradictory findings. Firstly, a multi-cultural study conducted in South Africa by O'Keefe and Wood (1996) found that gender, as well as race, had little effect on QOL. The authors suggest that, due to the relatively small sample size, the overwhelming effect of HIV infection on QOL might possibly have masked the effect of race and gender. Second, a Venezuelan study of 106 HIV-positive individuals by Bastardo and Kimberlin (1998) also found gender not to be a significant predictor of QOL as measured by the Medical Outcome Study (MOS) SF-36. This was confirmed by Lamping et al. (1991). Future research needs to consider these discrepancies and investigate possible variables impacting on QOL as they manifest themselves in men and women. Studies that focus on QOL in HIV-positive women might shed some light on factors that could be playing a role in reported gender differences.

It has been suggested that HIV infection is the chronic health condition associated with lowest QOL (Lamping et al., 1996). This was confirmed by an American study where 273 HIV-positive women and 237 HIV-negative women reported on their QOL. HIV-positive women were found to have significantly lower scores on all measures of QOL, except the mental health dimension of the MOS-HIV (McDonnell et al., 1999).

However, in a study comparing the QOL of 62 HIV-positive women with the norms of women suffering from 13 different chronic conditions, it was found that, with the exception of women suffering from depression and HIV, scores on mental health were generally higher than on physical health (Lamping et al., 1996). It would therefore seem as if mental health in HIV-positive women is by no means as robust as suggested by McDonnell et al. (1999).

In a study of depressive symptoms among African American women with HIV disease, it was found that their mean depressive symptom score was considerably higher than the published mean for female normative samples, and positively correlated with poorer QOL (Moneyham et al., 2000). In a comparison between QOL measures for low-income Caucasian and African American

women, the authors also found African American women to have a significantly poorer QOL, compared to their Caucasian counterparts (Israelski, Eversley, Janjua & Smith, 1998).

In a US study of 264 HIV infected women various factors were identified as having an impact on QOL in terms of their daily functioning, general anxiety and HIV symptoms. Limited daily functioning was predicted by stigma, fatalism, employment status, and stage of disease. General anxiety was predicted by emotional distress, intrusion and marital status, while HIV symptoms were predicted by material resources, disclosure, intrusion, age, employment status and race (Sowell et al., 1997). The results of this study support the hypothesis that social and psychological factors are important in their influence on QOL in women with HIV infection, but does not sufficiently elucidate the complex interplay of these factors. In another study of predominantly African American women unemployment, a history of injection drug use and a higher age, showed a positive correlation with lower QOL (Smith, Feldman, De Hovitz, Chirgwin & Minkoff, 1996). Recent immigrants and single mothers have been found to have the lowest QOL on all dimensions (Lamping et al., 1996).

A longitudinal QOL assessment in pregnant women with HIV confirmed that perceived QOL differs between HIV-negative and HIV-positive pregnant women, with the latter showing increased health distress and worse health transition during antenatal visits. Six months postpartum this group also reported decreased cognitive and social functioning. This can be ascribed to the disease process, and other life events associated with pregnancy and birth (Larrabee, Monga, Eriksen & Helfgott, 1996).

Sarna et al. (1999) conducted an exploratory descriptive study to describe QOL in a sample of 44 pregnant women with symptomatic HIV/AIDS. QOL was measured every two months over a four month period. Interestingly, a significant improvement in QOL on the physical and psychosocial scales was found during this period. However, the most prevalent disruptions in these women's lives were in the psychosocial domain, with married women being more vulnerable to disruptions in QOL over time. Sowell et al. (1997) found a similar correlation between marital status and QOL. The authors suggest that anxiety and distress could be ascribed to the additional demands of a marital relationship while having to cope with a debilitating illness at the same time.

The above findings suggest interesting gender differences with regard to QOL in HIV/AIDS. The literature clearly states that women's functional roles in society, coupled with their social and economic status, affect their experience of living with the illness. As gender roles evolve, these findings need to remain under scrutiny. This also applies to studies exploring the experiences of pregnant women and mothers as the ongoing debates around issues of childbearing have a direct influence on QOL.

Despite the common view that research has been male orientated in its focus, this seems to be only true with regard to the gay and injection drug user populations. The experience of HIV-positive heterosexual men has been much neglected and should receive urgent attention. For instance, sexuality in the face of altered health status, as well as the burden of being the provider within a family where there might be multiple infections, are some of the issues that could be explored.

There is sufficient evidence to suggest that gender, in conjunction with sociodemographic and other variables, play a significant role in the experienced QOL of HIV-positive individuals. A clearer understanding of how these factors impact on QOL and the needs and expectations of men and women, would enable health care workers to individualize support strategies aimed at enhancing QOL throughout the course of the disease.

4.8 Disease progression

Evaluating physical well-being and symptomatology was one of the earliest concerns in the medical treatment of symptomatic HIV and AIDS patients, mostly to establish the efficacy of treatment regimens and intervention outcomes (Kelly et al., 1993). Subsequent research about the impact of disease stage, disease progression and symptom severity as factors influencing QOL in general has expanded and currently represents a growing field of study.

Due to the complex nature of the disease and the multiple health problems associated with it, models for understanding the impact of disease on QOL need to be flexible. Nichols' Adjustment Reaction Model (1985) outlines four stages of adjustment, the first being the crisis stage associated with shock, trauma and devastation. This is followed by the transitional stage when

patients are faced with the reality of their diagnosis. During this stage patients often express feelings such as anger, guilt and depression. Once acceptance is reached, patients manage to take control of their situation and regain a sense of self-determination. The final stage, referred to as the preparatory stage, signifies a period of increased dependency in the face of imminent death. Not only do each of these stages represent different phases in disease progression, but also in psychological needs. Given the unpredictable ebb and flow of symptoms, individuals vacillate between these stages, each of which manifests different emotional needs (Murphy & Melby, 1999).

The literature has consensus about the fact that the moment following diagnosis is particularly traumatic and difficult to come to terms with (Firn & Norman, 1995; Murphy & Melby, 1999). Kelly and Murphy (cited in Murphy & Melby, 1999) identified fear and anxiety as one of the causes why some people avoid contact with health care workers for years on end. Leiberich et al. (1991) make the point that individuals often remain in the evasive-regressive coping mode for too long.

However, other studies presented more optimistic results. Following the initial phase of sorrow and lack of orientation regarding their future, findings show that most HIV-positive persons seem to deal with the demands of their illness effectively and report good QOL (Friedland et al., 1996; Leiberich et al., 1997; Remien, Rabkin, Katoff & Wagner, 1993). As has already been referred to, there is sufficient evidence that QOL may even be enhanced with the advent of a serious illness which is said to activate new and meaningful spiritual dimensions of life (Chuang, Devins, Hunsley & Gill, cited in Friedland et al., 1996; Coward, 1994; Gloersen et al., cited in Friedland et al., 1996; Rabkin, Remien, Katoff & Williams, 1993).

In the relatively small sample of HIV-positive participants, Chidwick and Borrill (1996) found that adjustment and coping improved after at least two years following diagnosis. In a study of coping styles and psychosocial adjustment of HIV-positive young gay men, Goggin (1993) found evidence of increasing psychosocial adjustment, especially after disclosure of HIV status or due to shifts in health status. Kalichman et al. (1996) found that, with the exception of those adopting an escape-avoidance style of coping, HIV-positive individuals become socially reconnected with time and experience less emotional distress.

There has been consistent evidence that an escalation in symptoms directly translates into a reduction in QOL (Manck et al., 1998; Smith et al., 1996). In a multicultural study of 205 symptomatic HIV-positive individuals, Cunningham et al. (1998b) concluded that the presence, number and severity of symptoms are strongly related to QOL. A number of longitudinal psychometric and descriptive studies showed that, as patients developed more symptoms, their physical, social and sexual functioning dropped significantly while psychological functioning remained unaltered or even improved (De Boer, Van Dam & Sprangers, 1995; Lubeck & Fries, 1992; Hays et al., 2000; Lubeck & Fries, 1993).

This was confirmed in a longitudinal comparative study of 24 asymptomatic and 20 symptomatic HIV-infected patients. As expected, the symptomatic group had significantly lower scores on physical functioning. The presence or absence of symptoms, however, had no significant effect on psychological well-being (Dijkgraaf et al., 1992). Despite the seeming robustness of the mental health domain, QOL showed a reduction of note. In a Venezuelan population Bastardo and Kimberlin (1998) confirmed this positive correlation between the presence of symptoms and a reduction of QOL, except on the mental health scale.

However, in a study of African American and Caucasian HIV-positive women, Israelski et al. (1998) found a positive correlation between an increase in symptoms and a decrease in QOL on both physical and mental health domains. These findings raise research questions about the emotional and mental stressors particular to HIV-positive women and their impact on QOL.

Apart from the physical distress caused by the illness itself, some treatment regimens have been known to cause side-effects that have a detrimental effect on QOL. Franchi and Wentzel (1998) reviewed studies on health-related QOL that are of particular relevance in this regard. They also concluded that health-related QOL scores do not always correlate with disease stage or health indices, but rather with the presence or absence of symptoms. Sousa, Holzemer, Henry and Slaughter (1999) confirmed these findings in their recent study of 142 AIDS patients.

Decrements in T4 cell and total lymphocyte count have been seen as significant predictors of disease progression and the development of AIDS. Several studies have investigated possible predictors of these immune measures as a way of exploring health-related QOL. In a sample of

11 asymptomatic homosexual males, high life stressor impact and a passive coping style were positively related to a deterioration in immune measures and consequently also a reduction in QOL (Goodkin et al., 1992b). Goodkin et al. (1992a) confirmed that an active coping style has a deterrent effect on the loss of natural killer cell function and subsequently on disease progression.

Contrary to these findings, a seven-year Dutch study of 181 gay men concluded that avoidance coping was not related to the development of AIDS-defining clinical symptoms. Active cognitive and behavioural coping were not related to disease progression either (Mulder, De Vroome, Van Griensven, Antoni & Sandfort, 1999). This study has the benefit of a relatively large sample size and an extensive follow-up period. In order to better understand the relationship between coping style and disease progression, more research is required in future.

Hays et al. (2000) conducted an extensive health-related QOL study. An impressive sample of 2864 HIV symptomatic and asymptomatic infected adults were compared with both the general American population and patients suffering from other chronic illnesses. On the physical functioning scale the asymptomatic HIV-positive group and the general American population had similar scores that were significantly higher than those of symptomatic HIV-positive and AIDS individuals. As was also found by Lamping et al. (1996), scores obtained by AIDS sufferers were significantly lower than those of patients suffering from other chronic diseases. This was true not only for physical functioning, but also on the emotional well-being scale. Emotional well-being was comparable among patients with various stages of HIV disease, but was significantly worse than the general population and patients with other chronic diseases, except depression. These findings yet again confirm the positive correlation between an increase in symptoms and a reduction in QOL (Hays et al., 2000).

There seems to be consensus about the impact made by the presence or absence of symptoms, and in particular on the domain of physical well-being in QOL. The relationship between disease progression or disease status, and emotional well-being in HIV, has also been confirmed and explained through models such as Nichols' Adjustment Reaction Model (1985) discussed above or grief models such as the one suggested by Kubler-Ross (Murphy & Melby, 1999).

In addition to trends identified by the literature, the impact of disease progression on QOL seems interlinked with a number of other variables such as social support, gender or spiritual orientation. A more sophisticated understanding of the synergy and inter-relatedness of these factors through the various stages of the disease is required, together with an exploration of the factors that contribute to making HIV the chronic disease that most severely impacts on QOL. Knowledge about disease progression will be beneficial in identifying periods of increased vulnerability as well as the development and implementation of relevant support strategies.

5. CONCLUSIONS

Despite the success of new medical treatments for HIV, there is a continuing and pressing need for a better understanding of factors that influence QOL (Doyle, Petrak, Skinner, Smith & Hedge, 1998). Most research findings discussed in this article confirm that QOL has a direct impact on the progression of the disease and therefore on survival time (Leserman et al., 1992; Rabkin et al, 1993). It follows that a better understanding of the nature and determinants of QOL for HIV patients will yield valuable intervention guidelines within a biopsychosocial framework.

There is a deluge of research on the impact of social support, coping skills and related mental adjustment as buffer against the stress of being HIV-positive. As most of these studies focus on the impact of only one of these factors, relatively little is known about the inter-correlations and combined effects on QOL for HIV patients. It has been suggested that these concepts could be integrated (e.g. to view social support as a coping resource). Integrating these concepts seems promising in unravelling adaptation to HIV.

In addition, coping strategies, as well as social support, have been described as potentially adaptive or maladaptive. Further research needs to be done in an attempt to explicate the relationship between these factors and disease progression, level of adaptation and post-diagnosis time lapse.

Defining the relationship between social support and coping skills also remains a future research requirement. This will demand a more sophisticated understanding of all variables impacting on

the psychological well-being of people living with HIV. Up to now the existing body of research has shed little light on socio-demography and life stress as antecedents of HIV QOL. Initially QOL research focused on the experiences of a male population and minority groups such as sex workers and injection drug users. In recent years the disease profile has shifted dramatically with heterosexual women of childbearing age being the most vulnerable to the disease. Despite this shift, research has been slow and sporadic in realigning its focus with HIV-related QOL in the female population.

The South African context promises to be a particularly challenging field of study due to the complex interplay between HIV/AIDS and socio-economic factors such as poverty, the migrant labour system, illiteracy, lack of formal education, low status of women, stigmatization and discrimination (Allen et al., 2000). All these factors, especially when they occur together, compound the stress experienced by many HIV-positive individuals and determine the resources available to them. Following a study of the stressors and stress of being HIV-positive, Thompson et al. (1996) concluded that QOL might be improved by interventions that help individuals to have a sense of autonomy and optimism in their lives and by programmes that reduce conflict with significant others.

This survey confirms that a myriad of variables correlate with QOL. Hypotheses about causality and inter-relatedness can be found in the literature, but for the most part satisfactory explanations are still lacking. These include factors such as stigmatization, guilt and shame, which form an integral part of people's experience of the HIV disease and will inevitably have an effect on QOL (Smith et al., 1996) and go hand in hand with the so-called conspiracy of silence and isolation that surrounds the illness. Likewise, loss of employment and financial difficulties exacerbate an already stressful life situation. Coping strategies and social support co-exist in a particular culture and within the individual's unique internal and external contexts. Consequently coping with HIV is a complex phenomenon involving multiple and interacting variables that require further investigation.

For findings to be satisfactory, there is a need for large, mixed samples to be more representative of all social strata. This will facilitate group comparisons and make results generalizable to the broader population. Qualitative research would also afford one the opportunity to better

understand the unique experiences of HIV-positive individuals and their immediate social context. Given the distinct phases in disease progression and adaptation, research would also be much enriched by longitudinal studies starting shortly after diagnosis and extending over all stages of the disease. The existing body of research also shows a clear neglect in the measurement of cognitive disruptions such as loss of attention, concentration and memory. As these factors have an impact on daily functioning, QOL research needs to take more cognisance thereof.

Finally, in the absence of satisfactory treatment strategies or a cure for HIV/AIDS, as well as the evidence of a potential 10 to 12 year life expectancy, there is an increasing need to understand the intricacies of factors affecting QOL in HIV/AIDS. Knowledge pertaining to the psychological and mental adjustment to HIV would directly inform therapeutic intervention programmes aimed at improving multidimensional QOL. Not only will such an investigation offer a deeper understanding of the unique challenges and coping strategies utilized, but will also validate the difficulties experienced by people living with HIV and meet their needs. This will be a significant secondary gain, as satisfaction with care positively correlates with improved health outcomes and adherence to therapy.

In conclusion, it can be said that ensuring optimal QOL in people living with HIV/AIDS is a key objective that requires careful consideration and focused research. It would further facilitate the identification of individual needs and concerns, and directly inform much needed care plans.

6. REFERENCE LIST

Abetz, L., McGrath, C., Grant, D., & Anderson, P. (1998). Coping with HIV/AIDS: Results from a qualitative study. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Allen, D.M., Simelala, N.P., & Makubalo, L. (2000). Epidemiology of HIV/AIDS in South Africa. Southern African Journal of HIV Medicine, 1(1), 9-11.

Alonzo, A.A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. Social Science and Medicine, 41, 303-315.

Avis, N.E., Smith, K.W., Mayer, K., & Swislow, L. (1997). Gender differences in quality of life among HIV-positive men and women. Paper presented at the National Conference on Women and HIV, San Francisco, USA.

Bastardo, Y.M., & Kimberlin, C.L. (1998). Relationship between quality of life and social support in HIV-infected persons in Venezuela. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Berer, M., & Ray, S. (1993). Women and HIV/AIDS. Great Britain: Butler and Tanner Publishers.

Beresford, B. (2001, March 23-29). Doubt on accuracy of AIDS stats. Mail & Guardian, p. 6.

Blaney, N.T., Goodkin, K., Feaster, D., Morgan, R., Baum, M., Wilkie, F., Szapocznik, J., & Eisdorfer, C. (1992). Life events and active coping style predict health status in early HIV-1 infection. Paper presented at the International Conference on AIDS, Amsterdam, Netherlands.

Bloom, F. (1996). Quality of life of gay men living in the HIV spectrum: Integrating illness experience with life story. Paper presented at the International Conference on AIDS, Vancouver, Canada.

Breitbart, W. (1996). Pain management and psychosocial issues in HIV and AIDS> American journal of Hospital and Palliative Care, 13(1), 20-29.

Brieger, M., Leiberich, P., Schumacher, K., & Low, P. (1996). Quality of life, depressive reactions and coping: Results of a 4-year longitudinal study. Paper presented at the International Conference on AIDS, Vancouver, Canada.

Britton, P.J., Zarski, J.J., & Hobfoll, E. (1993). Psychological distress and the role of significant others in a population of gay/bisexual men in the era of HIV. AIDS Care, 5(1), 43-55.

Brook, D.W., Brook, J.S., Richter, L., Whiteman, M., Win, P.T., Masci, J.R., & Roberto, J. (1999). Coping strategies of HIV-positive and HIV-negative female injection drug users: A longitudinal study. AIDS Education and Prevention, 11(5), 373-388.

Byrnes, D., Antoni, M., Goodkin, K., Ironson, G., Asthana, D., Efantis-Potter, J., Simon, T., Munajj, J., & Fletcher, M.A. (1997). Stressful events, repressive coping, pessimism and natural killer cell toxicity in women with human immunodeficiency virus and human papillomavirus. Paper presented at the National Conference on Women and HIV. San Francisco, USA.

Campbell, T., & Kelly, M. (1995). Women and AIDS in Zambia: A review of the psychosocial factors implicated in the transmission of HIV. AIDS Care, 7(3), 365-373.

Catalan, J. (1990). Psychiatric manifestations of HIV disease. Bailliere's Clinical Gastroenterology, 4, 547-562.

Catalan, J., Meadows, J., & Douzenis, A. (2000). The changing pattern of mental health problems in HIV infection: The view from London, UK. AIDS Care, 12(3), 333-341.

Chandra, P.S., Ravi, V., Desai, A., & Subbakrishna, D.K. (1998). Anxiety and depression among HIV-infected heterosexuals: A report from India. Journal of Psychosomatic Research, 45(5), 401-409.

Chidwick, A., & Borrill, J. (1996). Dealing with a life-threatening diagnosis: The experience of people with human immunodeficiency virus. AIDS Care, 8(3), 271-284.

Clement, U., & Schonneson, L.N. (1998). Subjective HIV attribution theories, coping and psychological functioning among homosexual men with HIV. AIDS Care, 10(10), 355-363.

Cohen, M., & Fischer, L. (1996). The meanings of quality of life among health care providers and people living with HIV/AIDS and their relationship to treatment. Paper presented at the International Conference on AIDS, Vancouver, Canada.

Cohen, S.R., Hassan, A.A., Lapointe, B.J., & Mount, B.M. (1996). Quality of life in HIV disease as measured by the McGill quality of life questionnaire. AIDS, 10(12), 1421-1427.

Coons, H.L., Harwell, T.S., Witek, J., Spence, M.R., & Striepe, M.I. (1997). Assessment of quality of life in women with HIV/AIDS. Paper presented at the National Conference of Women and HIV, San Francisco, USA.

Coward, D.D. (1994). Meaning and purpose in the lives of persons with AIDS. Public Health Nursing, 11(5), 331-336.

Crandles, S., Sussman, M., Berthaud, M., & Sunderland, A. (1992). Development of a weekly support group for caregivers of children with HIV disease. AIDS Care, 4(3), 339-352.

Crystal, S., Bilder, S., Merzel, C., & Sambamoorthi, U. (1993). Social support, coping, and psychological distress among persons with HIV disease. Paper presented at the International Conference on AIDS, Berlin, Germany.

Crewe, M. (1992). AIDS in South Africa. New York: Creda Press.

Cunningham, W.E., Hays, R.D., Williams, K.W., Beck, K.C., Dixon, W.J., & Shapiro, M.F. (1995). Access to medical care and health-related quality of life for low-income persons with symptomatic human immunodeficiency virus. Medical Care, 33(7), 739-754.

Cunningham, W.E., Hays, R.D., Ettl, M.K., Dixon, W.J., Liu, R.C., Beck, C.K., & Shapiro, M.F. (1998a). The prospective effect of access to medical care on health-related quality of life outcomes in patients with symptomatic HIV disease. Medical Care, 36(3), 295-306.

Cunningham, W.E., Shapiro, M.F., Hays, R.D., Dixon, W.J., Visscher, B.R., George, W.L., Ettl, M.K., & Beck, C.K. (1998b). Constitutional symptoms and health-related quality of life in patients with symptomatic HIV disease. American Journal of Medicine, 104(2), 129-136.

Cu-Uvin, S., Flanigan, T.P., Rich, J.D. (1996). Human immunodeficiency virus infection and acquired immunodeficiency syndrome among North American women. American Journal of Medicine, 101, 316-322.

De Boer, J.B., Van Dam, F.S., & Sprangers, M.A. (1995). Health-related quality-of-life evaluation in HIV-infected patients: A review of the literature. Pharmacoeconomics, 8(4), 291-304.

De Genova, M.K., Patton, D.M., Jurich, J.A., & MacDermid, S.M. (1994). Ways of coping among HIV-infected individuals. Journal of Social Psychology, 134(5), 655-663.

Di Franceisco, W.M., Heckman, T.G., & Somlai, A.M. (1997). Predictors of satisfaction with life among women living with HIV/AIDS. Paper presented at the National Conference on Women and HIV, San Francisco, USA.

Dijkgraaf, M.G., Bonsel, G.J., Geels, R.M., Vrehen, H.M., Jager, J.C., & Borleffs, J.C. (1992). Kwaliteiten van leven bij personen met een HIV-infectie, gezien in een academisch ziekenhuis. Nederlandse Tijdschrif van Geneeskunde, 136(43), 2123-2126.

Donini, S., Mirandola, M., Galvan, U., Serpelloni, G., & Kozina, G. (1992). Relationship between psychological adaptation and social network in HIV-positive patients. Paper presented at the International Conference on AIDS, Amsterdam, Netherlands.

Doyle, A.M., Petrak, J.A., Skinner, C.J., Smith, A.P., & Hedge, B. (1998). Mental health and quality of life in an east London out-patient HIV clinic population. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Een uit 9 in SA is MIV-positief, lui staat verslag. (One in 9 in SA is HIV-positive, according to report). (2001, March 21). Die Burger, p. 2.

Evian, C. (1993). Poverty: The social basis of AIDS in South Africa. Critical Health, 44, 22-26.

Fell, M., Newman, S., & Herns, M. (1993). Mood and psychiatric disturbance in HIV and AIDS: Changes over time. British Journal of Psychiatry, 162, 604-610.

Firn, S., & Norman, I.J. (1995). Psychological and emotional impact of an HIV diagnosis. Nursing Times, 91, 37-39.

Fleischman, J.A., Sherbourne, C.D., Crystal, S., Collins, R.L., Marshall, G.N., Kelly, M., Bozzette, S.A., Shapiro, M.F., & Hays, R.D. (2000). Coping, conflictual social interactions, social support, and mood among HIV-infected persons. American Journal of Community Psychology, 28(4), 421-453.

Folkman, S., Chesney, M., & Christopher-Richards, A. (1994). Stress and coping in caregivers partners of men with AIDS. Psychiatric Clinics of North America, 1, 35-53.

Franchi, D., & Wentzel, R.P. (1998). Measuring health-related quality of life among patients infected with human immunodeficiency virus. Clinically Infectious Diseases, 26(1), 20-26.

Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. AIDS Care, 8(1), 15-31.

Fukuda, K. (1994). Emotional state and way of coping in patients with AIDS and HIV infection. Paper presented at the International Conference on AIDS, Yokohama, Japan.

Fukunishi, I., Hayashi, M., Matsumoto, T., Negishi, M., & Moriya, H. (1997). Liaison psychiatry and HIV infection (I): Avoidance coping responses associated with depressive symptoms accompanying somatic complaints. Psychiatric and Clinical Neuroscience, 51(1), 1-4.

Gale, K. (2000). Stress, poor social support associated with faster progression of AIDS. American Journal of Psychiatry, 157, 1221-1228.

Gillman, P.R., & Newman, B.S. (1996). Psychosocial concerns and strengths of women with HIV infection: An empirical study. The Journal of Contemporary Human Services, March, 131-142.

Goggin, M. (1993). Coping styles and psychosocial adjustment of HIV-positive young gay men. Paper presented at the International Conference on AIDS, Berlin, Germany.

Goodkin, K., Blaney, N.T., Feaster, D., Fletcher, M.A., Baum, M.K., Mantero-Atienza, E., Klimas, N.G., Millon, C., Szapocznik, J., & Eisendorfer, C. (1992a). Active coping style associated with natural killer cell toxicity in asymptomatic HIV-1 seropositive homosexual men. Journal of Psychosomatic Research, 36(7), 635-650.

Goodkin, K., Fuchs, I., Feaster, D., Leeka, J., & Rishel, D.D. (1992b). Life stressors and coping style are associated with immune measures in HIV-1 infection: Preliminary report. International Journal of Psychiatry and Medicine, 22(2), 155-172.

Grassi, L., Righi, R., Sighinolfi, L., Makoui, S., & Ghinelli, F. (1998). Coping styles and psychosocial-related variables in HIV-infected patients. Psychosomatics, 39(4), 350-359.

Grassi, L., Rosti, G., Lasalvia, A. & Marangolo, M. (1993). Psychological variables associated with mental adjustment to cancer. Psycho-Oncology, 2, 11-20.

Grassi, L., & Sighinolfi, L. (1996). Psychosocial correlates of quality of life in patients with HIV infection. AIDS Patient Care and STDs, 10(5), 296-298.

Green, G. (1993). Editorial review: Social support and HIV. AIDS Care, 5(1), 87-103.

Green, J., Henderson, F., Tyrer, P., & Hedge, B. (1992). Subjective quality of life in persons with HIV disease. Paper presented at the International Conference on AIDS, Amsterdam, Netherlands.

Green, G. & Rademan, P. (1997). Evangelical leaders and people with HIV. AIDS Care, 9(6), 715-726.

Greer, S. & Watson, M. (1987). Mental adjustment to cancer: Its measurement and prognostic importance. Cancer Surveys, 6(3), 439-453.

Greer, S., Morris, T., & Pettingale, K.W. (1979). Psychological response to breast cancer: Effect on outcome. Lancet, 2, 785-787.

Gregson, S. (1994). Modelling the spread of HIV-1 in Zimbabwe: Determinants, demographic impact and socio-economic consequences. ZAINet AIDS News, 2(2), 2-7.

Griffiths, K., & Wilkens, E.G. (1993). Patterns of coping with an HIV-positive diagnosis. Paper presented at the International Conference on AIDS, Berlin, Germany.

Grimes, D.E., & Cole, F.L. (1996). Self-help and life quality in persons with HIV disease. AIDS Care, 8(6), 291-699.

Grundlingh, L. (1997). The nature and development of HIV/AIDS historiography. Acta Academica, 29(2), 1-26.

Hays, R., & Shapiro, M. (1992). An overview of generic health-related quality of life measures of HIV research. Quality of Life Research, 2, 99-107.

Hays, R., Turner, H., Catania, J., Mandel, J., & Coates, T. (1998). Social support, HIV symptoms and depression among gay men. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Heckman, T.G., Somlai, A.M., Kelly, J.A., Stevenson, L.Y., & Galdabini, K. (1996). AIDS Patient Care of STDs, 10(1), 37-43.

Heckman, T.G., Somlai, A.M., Sikkema, K.J., Kelly, J.A., & Franzio, S.L. (1997). Psychosocial predictors of life satisfaction among persons living with HIV infection and AIDS. Journal of Associated Nurses AIDS Care, 8(5), 21-30.

Heckman, T.G., Somlai, A.M., Kalichman, S.C., Franzoi, S.L., & Kelly, J.A. (1998). Psychosocial differences between urban and rural people living with HIV/AIDS. Journal of Rural Health, 14(2), 138-145.

Hays, R.D., Cunningham, W.E., Sherbourne, C.D., Wilson, I.B., Wu, A.W., Cleary, P.D., McCaffrey, D.F., Fleischman, J.A., Crystal, S., Collins, R., Eggan, F., Shapiro, M.F., & Bozette, S.A. (2000). American Journal of Medicine, 108(9), 714-22.

Hedge, B. (1991). Psychosocial aspects of HIV infection. AIDS Care, 3, 409-412.

Hedge, B., Slaughter, J., Flynn, R., & Green, J. (1993). Coping with HIV disease: Successful attributes and strategies. Paper presented at the International Conference on AIDS, Berlin, Germany.

Holzemer, W.L., Gygax, S.J., Skodol, W.H., Kemppainene, J.K., & Coleman, C. (1998). Validation of the quality of life scale: Living with HIV. Journal for Advanced Nursing, 28(3), 622-630.

Horowitz, M.J. (1978). Stress response syndromes. United States of America: Aronson.

Ingram, K.M., Jones, D.A., Fass, R.J., Neidig, J.L., & Song, Y.S. (1999). Social support and unsupportive social interactions: Their association with depression among people living with HIV. AIDS Care, 11(3), 313-329.

Israelski, D., Eversley, R., Janjua, S., & Smith, S. (1998). Race, HIV symptoms, recovery from drug abuse, and appointment adherence are associated with quality of life (QOL) among HIV infected women. Paper presented at the International Conference on AIDS, Berlin, Switzerland.

Jackson, H., & Kerkhoven, R. (1995). Developing AIDS care in Zimbabwe: A case for residential community centres. AIDS Care, 7(5), 663-673.

Kalichman, S.C., Sikkema, K.J., & Somlai, A. (1996). People living with HIV infection who attend and do not attend support groups: A pilot study of needs, characteristics and experiences. AIDS Care, 8(5), 589-599.

Karim, A.Q. (1998). Women and AIDS: The imperative for gendered prognosis and prevention policy. Agenda, 39, 15-25.

Kelly, P., Holman, S., Ehrlich, I., Driscoll, B., Chirgwin, K., & De Hovitz, J. (1993). Quality of life measurement in HIV positive women. Paper presented at the International Conference on AIDS, Berlin, Germany.

Kelly, B., Raphael, B., Burrows, G., Judd, F., Kernutt, G., Burnett, P., Perdices, M., & Dunne, M. (2000). Measuring psychological adjustment to HIV infection. International Journal of Psychiatry in Medicine, 30(1), 41-59.

Kennedy, C.A., Skurnick, J.H., Foley, M., & Louria, D.B. (1995). Gender differences in HIV-related psychological distress in heterosexual couples. AIDS Care, 7(1), 33-38.

Kennedy, C., Holland, B., Phillips, L., Buersmeyer, P., Ho, P., & Harrison, D. (1998). Quality of life correlates at an urban day treatment centre. Paper presented at the International Conference on AIDS, Berlin, Switzerland.

Krikorian, R., Kay, J., & Liang, W.M. (1995). Emotional distress, coping, and adjustment in human immunodeficiency virus infection and acquired immune deficiency syndrome. Journal of Nervous Mental Disorders, 183(5), 293-298.

Lamping, D.L., Gilmore, N., Grover, S.A., Tsoukas, C., Falutz, J., Hamel, M., & Di Meco, P. (1992). Social support and health-related outcomes in persons with HIV infection. Paper presented at the International Conference on AIDS, Amsterdam, Netherlands.

Lamping, D.L., Sewitch, M., Clark, E., Ryan, B., Gilmore, N., Grover, S.A., Williams, J.I., Meister, C., Hamel, M., & Di Meco, P. (1991). HIV-related mental health distress in persons with HIV infection, caregivers, and family members/significant others: Results of a cross-Canada survey. Paper presented at the International Conference on AIDS, Florence, Italy.

Lamping, D.L., Dooley, M., Murcott, A., & Renton, A. (1996). Health-related quality of life in HIV-positive women. Paper presented at the International AIDS Conference, Vancouver, Canada.

Larrabee, K.D., Monga, M., Eriksen, N., & Helfgott, A. (1996). Quality of life assessment in pregnant women with the human immunodeficiency virus. Obstetric Gynecology, 88(6), 1016-1020.

Lazarus, R.S. (1981). The costs and benefits of denial. In B.S. Dohrenwend & B.P. Dohrenwend (Eds.), Stressful life events and their contexts (pp. 131-156). New Jersey: Rutgers University Press.

Lazarus, R.S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer.

Lefcourt, H.M. (1981). Locus of control and stressful life events. In B.S. Dohrenwend & B.P. Dohrenwend (Eds.), Stressful life events and their contexts (pp. 157-166). New Jersey: Rutgers University Press.

Leiberich, P., Engeter, M., Olbrich, E., Rubbert, A., Schumacher, K., Breiger, M., Kalden J.R., & Joraschy, P. (1997). Longitudinal development of distress, coping and quality of life in HIV-positive persons. Psychotherapy and Psychosomatics, 66, 237-247.

Leiberich, P., Reiser, J., Harrer, T., Kalden, J.R., Sprinkart, P., Wendler, J., Muller, M., & Olbrich, E. (1991). Evasive-aggressive coping in HIV-positives as indication for psychotherapy. Paper presented at the International Conference on AIDS, Florence, Italy.

Leiberich, P., Schumacher, K., Rubbert, A., Schwab, J., Olbrich, E., & Kalden, J.R. (1993). Low distress and high life quality in HIV-positives correlate with flexible coping. Paper presented at the International Conference on AIDS, Berlin, Germany.

Leserman, J., Petitto, J.M., Golden, R.N., Gaynes, B.N., Gu, H., Perkins, O., Silva, S.G., Folds, J.D., & Evans, D.L. (1992). Impact of stressful life events, depression, social support, coping and cortisol on progression of AIDS. American Journal of Psychiatry, 157(8), 1221-1228.

Lie, G.T., & Biswalo, P.M. (1996). HIV-positive patient's choice of a significant other to be informed about the HIV-test result: Findings from an HIV/AIDS counselling programme in the regional hospitals of Arusha and Kilimanjaro, Tanzania. AIDS Care, 8(3), 285-296.

Lindegger, G., & Crewe, M. (1997). HIV/AIDS: Managing the madness. In D. Foster, M. Freeman & Y. Pillay (Eds.), Mental Health Policy Issues for South Africa (pp. 263-278). Medical Association of South Africa: Multimedia Publications.

Lindegger, G., & Wood, G. (1994). The AIDS crisis: Review of psychological issues and implications, with special reference to the South African situation. South African Journal of Psychology, 25(1), 1-11.

Ling, S.U., Moore, R.D., Keruly, J.C., Guess, H.A., Lyketsos, C.G., Kaplan, B.H., & Royce, R.A. (1998). Depression, social support, and quality of life in HIV patients. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Lippmann, S.B., James, W.A., & Frierson, R.L. (1993). AIDS and the family: Implications for counselling. AIDS Care, 5(1), 71-78.

Lubeck, D.P., & Fries, J.F. (1992). Changes in quality of life among persons with HIV infection. Quality of Life Research, 1(6), 359-366.

Lubeck, D.P., & Fries, J.F. (1993). Quality of life after one year for persons at-risk for HIV infection. Paper presented at the International Conference on AIDS, Berlin, Germany.

Lutgendorf, S.K., Antoni, M.H., Ironson, G., Starr, K., Costello, N., Zuckerman, M., Klimas, N., Fletcher, M.A., Schneiderman, N. (1994). Psychosocial counselling to improve quality of life in HIV infection. Patient Education Counselling, 24(3), 217-235.

Maldonado, J., Israelski, D.M., Diamond, S., Chapman, A., Koopman, C., Gill, M., & Spiegel, D. (1998). Depression and CD4 cell count as predictors of quality of life in HIV-positive persons. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Manck, E., Claes, C., Gunther, G., Wulff, W., Graf von der Schulenburg, R.E., Schmidt, R.E., & Stoll, M. (1998). Impact of risk factor, clinical category and socio-economic data on quality of life in HIV infected outpatients. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

McDonnell, K.A., Gielen, A.C., O'Campo, P., & Burke, J.G. (1999). Using a quality of life measure to capture areas of unmet needs among HIV-positive and HIV-negative women. Paper presented at the National HIV Prevention Conference, Atlanta, USA.

McGrath, J.W., Ankrah, E.M., Schumann, D.A., Nkumbi, S., & Lubega, M. (1993). AIDS and the urban family: Its impact in Kampala, Uganda. AIDS Care, 5(1), 55-70.

Mello, J.H. (1996). Strategies for coping with HIV/AIDS in self-help groups. Paper presented at the International Conference on AIDS, Vancouver, Canada.

Mellors, M.P., Riley, T.A., & Erlen, J.A. HIV, self-transendence, and quality of life. Journal of Associated Nurses AIDS Care, 8(2), 59-69.

Melnick, S.L., Sherer, R., & Louis, T.A. (1994). Survival and disease progression according to gender of patients with HIV infections. Journal of the American Medical Association, 272(24), 1915-1921.

Meredith, K., Delaney, J., Horgan, M., Fisher Jr, E., & Fraser, V. (1997). A survey of women with HIV about their expectations for care. AIDS Care, 9(5), 513-522.

Moneyham, L., Hennessy, M., Sowell, R., Demi, A., Seals, B., & Mizuno, Y., (1998). The effectiveness of coping strategies used by HIV-seropositive women. Research in Nursing and Health, 21(4), 351-362.

Moneyham, L., Sowell, R., Seals, B., & Demi, A. (2000). Depressive symptoms among African American women with HIV disease. School of Nursing Practice, 14(1), 9-39.

Moos, R.H., & Tsu, V.D. (1977). The crisis of physical illness: An overview. In R.H. Moos (Ed.), Coping with physical illness (pp. 1-26). New York: Plenum Medical Book Company.

Murphy, M., & Melby, V. (1999). Psychological needs of patients with HIV disease: Reviewing the literature using Nichols' (1985) Adjustment Reaction Model as Framework. Journal of Psychiatric and Mental Health Nursing, 6, 101-106.

Mulder, C.L., De Vroome, E.M., Van Griensven, G.J., Antoni, M.H., & Sandfort, T.G. (1999). Avoidance as a predictor of the biological course of HIV infection over a 7-year period in gay men. Health Psychology, 18(2), 107-113.

Nannis, E., Semple, S., & Patterson, T. (1995). HIV-positive women and coping: Psychosocial predictors of 'fighting spirit'. Paper presented at the HIV Infection in Women Conference, Washington DC, USA.

Nannis, E.D., Patterson, T.L., & Semple, S.J. (1997). Coping with HIV disease among seropositive women: Psychosocial correlates. Women's Health, 25(1), 1-22.

Nichols, S. (1985). Psychosocial reactions of persons with AIDS. Annals of Internal Medicine, 103, 765-767.

Nunes, J.A., Raymond, S.J., Nicholas, P.K., Leuner, J.D., & Webster, A. (1995). Social support, quality of life, immune function, and health in persons living with HIV. Journal of Holistic Nursing, 13(2), 174-198.

O'Keefe, E.A., & Wood, R. (1996). The impact of HIV infection on quality of life in a multiracial South African population. Quality of Life Research, 5, 275-280.

Osowiecki, D.M., Cohen, R.A., Morrow, K.M., Paul, R.H., Carpenter, C.C., & Boland, R.J. (2000). Neurocognitive and psychological contributions to quality of life in HIV-1-infected women. AIDS, 14(10), 1327-1332.

Pepler, C., Seguin, E., Edgar, L., Gilmore, N., Ladd, H., Sampalis, J., & Gravel, R. (1998). Coping and control: Variation and relationships with health in men living with HIV/AIDS. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Pinder, K.L., Ramirez, A.J., Richards, M.A., & Gregory, W.M. (1994). Cognitive responses and psychiatric disorder in women with operable breast cancer. Pscyho-Oncology, 3, 129-137.

Pivar, I., & Temoshok, L. (1990). Coping strategies and response styles in homosexual symptomatic men. Paper presented at the International Conference on AIDS, San Francisco, USA.

Rabkin, J., Remien, R., Katoff, L., & Williams, J. (1993). Resilience in adversity among long-term survivors of AIDS. Hospital and Community Psychiatry, 44, 162-167.

Reid, E. (1994). Approaching the HIV epidemic: The community's response. AIDS Care, 6(5), 551-557.

Remien, R.H., Rabkin, J., Katoff, L., & Wagner, G. (1993). Medical and psychological characteristics of extended long-term survival with AIDS: A follow-up study. Paper presented at the International Conference on AIDS, Berlin, Germany.

Rose, M., & Clarke-Alexander, B. (1996). Quality of life and coping styles of HIV-positive women with children. Journal of Associated Nurses AIDS Care, 7(2). 28-34.

Rosengard, C., & Folkman, S. (1997). Suicidal ideation, bereavement, HIV serostatus and psychosocial variables in partners of men with AIDS. AIDS Care, 9(4), 373-385.

Ross, M.W., Hunter, C.E., Condon, J., Collins, P., & Begley, K. (1994). The Mental Adjustment to HIV scale: Measurement and dimensions of response to AIDS/HIV disease. AIDS Care, 6(4), 407-411.

Rubin, H.C., Patterson, T.L., Atkinson, J.H., Kaplan, R.M., Koch, W.L., McCutchan, J.A., Chandler, J.L., & Grant, I. (1994). Quality of life in people with depressive symptoms and HIV. Paper presented at the International Conference on AIDS, Yokohama, Japan.

Sarason, I.G., Sarason, B.R., & Pierce, G.R. (1997). Social support: The search for theory: Special issue: Social support in social and clinical psychology. Journal of Social and Clinical Psychology, 9, 133-147.

Sarna, L., Van Servellen, G., Padilla, G., & Brecht, M.L. (1999). Quality of life in women with symptomatic HIV/AIDS. Journal of Advanced Nursing, 30(3), 597-605.

Schreurs, .M.G., & De Ridder, D.T.D. (1997). Integration of coping and social support perspectives: Implications for the study of adaptation to chronic diseases. Clinical Psychology Review, 17(1), 88-112.

Semple, S.J., Patterson, T.L., & Temoshok, L.R. (1993). Identification of psychobiological stressors among HIV-positive women. Women and Health, 20(4), 15-36.

Sewpal, V. & Mahlalela, T. (1998). The power of the small group: From crisis to disclosure. Agenda, 39, 35-43.

Sherbourne, C.D., Hays, R.D., Fleishman, J.A., Vitiello, B., Magruder, K.M., Bing, E.G., McCaffrey, D., Burnam, A., Longshore, D., Eggan, F., Bozzette, S.A., & Shapiro, M.F. (2000). Impact of psychiatric conditions on health-related quality of life in persons with HIV infection. American Journal of Psychiatry, 157(2), 248-254.

Shumaker, S.A., Ellis, S., & Naughton, M. (1997). Assessing health quality of life in HIV disease: Key measurement issues. Quality of Life Research, 6(6), 475-480.

Siegel, K., Gluhoski, V.L., & Karus, D. (1997a). Coping and mood in HIV-positive women. Psychological Reports, 81(2), 435-442.

Siegel, K., Karus, D.G., & Raveis, V.H. (1997b). Psychological and psychosocial adjustment of HIV-infected women: Race/ethnic comparisons. Paper presented at the National Conference on Women and HIV, San Francisco, USA.

Sikkema, K.J., Kalichman, J.A., Kelly, J.A., & Koob, J.J. (1995). Group intervention to improve coping with AIDS-related bereavement: Model development and an illustrative clinical example. AIDS Care, 7(4), 463-475.

Singh, N., Berman, S., Swindells, S., Justis, J., Squier, C., Mohr, J., & Wagener, M.M. (1998). Quality of life in HIV infection: Role of social support, pessimism, and coping. Paper presented at the International Conference on AIDS, Geneva, Switzerland.

Smith, M.Y., Feldman, J., De Hovitz., J.A., Chirgwin, K., & Minkoff, H. (1996). Health-related quality of life of HIV-infected women: Evidence for the reliability, validity and responsiveness of the Medical Outcome Study Short-Form 20. Quality of Life Research, 5(1), 47-55.

Solomon, L., Gleghorn, A., Astemborski, J., & Vlahov, D. (1993). Sex differences in coping and social support among HIV seropositive and seronegative injection drug users. Paper presented at the International Conference on AIDS, Berlin, Germany.

Sowell, R.L., Seals, B.F., Moneyham, L., Demi, A., Cohen, L., & Brake, S. (1997). Quality of life in HIV-infected women in the south-eastern United States. AIDS Care, 9(5), 501-512.

Sowell, R., Moneyham, L., Hennesey, M., Guillory, J., Demi, A., & Seals, B. (2000). Spiritual activities as a resistance for women with human immunodeficiency virus. Nursing Research, 49(2), 73-82.

Sousa, K.H., Holzemer, W.L., Henry, S.B., & Slaughter, R. (1999). Dimensions of health-related quality of life in persons living with HIV disease. Journal of Advanced Nursing, 29(1), 178-187.

Spalding, A.D. (1995). Racial minorities and other high-risk groups with HIV and AIDS at increased risk for psychological adjustment problems in association with health locus of control orientation. Social Work and Health Care, 21(3), 81-114.

Stevens, P.E., & Tighe Doerr, B. (1997). Trauma of discovery: Women's narratives of being informed they are HIV-infected. AIDS Care, 9(5), 523-538.

Stowe, A., Ross, M.W., Wodak, A., Thomas, G.V. & Larson, S.A. (1993). Significant relationships and social supports of injecting drug users and their implications for HIV/AIDS services. AIDS Care, 5(1), 23-33.

Strebel, A., & Lindegger, G. (1998). Power and responsibility: Shifting discourses of gender and HIV/AIDS. Psychology in Society, 24, 4-20.

Sundby, J. (1999). Are women disfavoured in the estimation of disability adjustment life years and the global burden of disease? Scandinavian Journal of Public Health, 27(4), 279-285.

Swanepoel, T. (2001, March 15). Regop graf toe. (Upright to the grave). Die Burger, p. 11.

Swindells, S., Justis, J., Mohr, J., Berman, S., Squier, C., Wagener, M., & Singh, N. (1998). Quality of life in HIV infection and HAART. Paper presented at the Interscience Conference on Antimicrobiotic Agents and Chemotherapy, San Francisco, USA.

Swindells, S., Mohr, J., Justis, J.C., Berman, S., Squier, C., Wagener, M.M., & Singh, N. (1999). Quality of life in patients with human immunodeficiency virus infection: Impact of social support, coping style and hopelessness. International Journal of STD's and AIDS, 10(6), 383-391.

Tallis, V. (1998). AIDS is a crisis for women. Agenda, 39, 6-14.

Taylor-Brown, S. (1993). HIV-positive women: Finding a voice in the AIDS pandemic. In V.J. Lynch, G.A. Lloyd, & M.F. Fimbres (Eds.), The changing face of AIDS: Implications for social work practice. London: Auburn House.

Thompson, S.C., Nanni, C., & Levine, A. (1996). The stressors and stress of being HIV-positive. AIDS Care, 8(1), 5-14.

Thoits, P.A. (1986). Social support as coping assistance. Journal of Consulting and Clinical Psychology, 54, 416-423.

UNAIDS WHO (1998). Report on the global HIV/AIDS epidemic.

Vaux, A. (1990). An ecological approach to understanding and facilitating social support: Special Issue: Predicting, activating and facilitating social support. Journal of Social and Personal Relationships, 7, 507-518.

Van Zyl, J. (1999, September 3). SA, raak oopkop oor VIGS. (SA, become realistic about about AIDS). Finansies en Tegniek, pp. 10-12.

Watson, M., Greer, S., & Bliss, J.M. (1989). Mental Adjustment to Cancer Scale Users' Manual. Sutton: Institute of Cancer Research.

Whiteside, A., & Sunter, C. (2000). AIDS: The challenge for South Africa. Cape Town: Human & Rousseau Tafelberg.

Wolf, T.M., Balson, P.M., Morse, E.V., Simon, P.M., Gaumer, R.H., Dralle, P.W., & Williams, M.H. (1991). Relationships of coping style to affective state and perceived social support in asymptomatic and symptomatic HIV-infected persons: Implications for clinical management. Journal of Clinical Psychiatry, 52(4), 171-173.

Wu, A.W., & Rubin, H. (1992). Measuring health status and quality of life in HIV and AIDS. Psychology and Health, 6, 251-264.

Zander, K., Jager, H., Palitzsch, M., Poppinger, J., Von Steinbuchel, N., & Bullinger, M. (1993). Health related quality of life (HRQL) in HIV disease: Influence of symptom load, functioning, mood and coping styles. Paper presented at the International Conference on AIDS, Berlin, Germany.

Zarazaga Monzon, A., Culebras, J.M., Gomez Candela, C., & Cos, A.I. (1998). Evaluation of the Quality of Life in artificial nutrition. Nutritional Hospital, 13(1), 1-7.

Zich, J., & Temoshok, L. (1987). Perceptions of social support in men with AIDS and ARC: Relationships with distress and hardiness. Journal of Applied and Social Psychology, 17, 193-215.